

ABSTRACT

Despite successful efforts made by the South African government to implement youth-friendly services in public clinics, none of these efforts have formally evaluated youth engagement as an integral framework to improve health service delivery to young adults (16-24 years). The youth engagement framework is a participatory research approach, where young people and adults merge their efforts to work towards a common goal while sharing knowledge and power. The objective of our study was to evaluate the effectiveness of the Youth Engagement (YE) approach as part of a larger adolescent HIV cohort study. AYA ZAZI ('knowing themselves' in the Zulu language) is an interdisciplinary longitudinal cohort study at the Perinatal HIV Research Unit (PHRU) which aims to link HIV socio-behavioural patterns and clinical characteristics among youth age 16-24 years living in Soweto, South Africa. The AYA ZAZI study adopted a youth engagement approach where youth (16-24 years) play an active role as research staff members and participants while receiving the guidance and support of adult allies. The AYA ZAZI cohort study has a mixed age group on staff, consisting of Adolescents and Young Adults (AYA) (16-24 years) staff, and adult allies (older than 25 years). To evaluate the YE approach in AYA ZAZI, we employed two data sources: anonymously written responses submitted via a suggestion box, as well as responses given during face-to-face interviews. The suggestion box was implemented in the youth lounge at the PHRU clinic to assess Adolescents and Young Adults (AYA) research participants' satisfaction with the AYA ZAZI research study. We also conducted face-to-face interviews with 5 (AYA) AYA ZAZI research participants (18-24 years), 4 youth AYA ZAZI research staff (16-24 years), and 4 AYA ZAZI "adult allies" staff (older than 25). Key findings from the youth engagement evaluation included young people feeling valued by staff members, and youth staff having new career aspirations as a result of interacting with adult staff members. Adopting a youth engagement approach created an effective communication space between adults and young people. Taken together, our results suggest that, when given a supportive environment where young people can engage with those of the same age group along with supportive adults, youth are more likely to partake in programs and services intended to benefit them.

INTRODUCTION

Participatory research is widely used in community-based programs, but the engagement of young people as partners in research, termed the youth engagement (YE) framework, is a relatively new concept (Pereira, 2007). Pereira defines it as: “Empowering all youth as valued partners in addressing and making decisions about issues that affect them personally and/or that they believe to be important. It is about adults working with youth to create opportunities for young people to become involved in and contribute to the betterment of an organization and/or community in which they live” (2007). In practice, this participatory research (PAR) approach involves an equal partnership between adults and young people in the planning and implementation of programs. This leads to skills development and community mobilization of young people, who are supported by adults in the decision making of implementing impactful strategies affecting the lives people in the same age group (Powers, J.L and Tiffany, J.S., 2006). Within the context of health research interventions and programs, a successful youth engagement approach could be an innovative way for young people to provide new ideas and implement relevant and effective strategies to enhance their engagement in health services.

There are two ways to implement the Youth Engagement framework. Ideally, the execution of the youth engagement approach requires young people to become collaborators at the initiation of a project, by partnering with them in strategizing all activities from start to finish (Pereira, 2007; UNICEF, 2004). An alternate approach to the YE is for adults to initiate the project(s) then collaborate with young people at later stages (Pereira, 2007; UNICEF, 2004). Both of these approaches can result in the discovery of new knowledge that is exchanged between youth and adults (IFRC, 2013; Powers, J.L and Tiffany, J.S., 2006). In practice, some initiatives have hired youth on a consultancy basis to seek their input whenever revision of youth program is needed; others have hired young people on staff (Pereira, 2007).

Ultimately, the YE approach aims to empower youth by treating them with respect and recognizing that young people are capable of making important decisions that benefit them. Benefits of the YE approach include the youth-adult mentorship, which leads to young people building skills and gaining career aspirations by learning from adult allies (Jarrett et al., 2005). When youth are engaged in the planning and implementation of social programs intended to benefit them, and when their input is put into action and valued by adults, young people are likely to encourage their peers to engage in these programs (Pereira, 2007; UNICEF, 2004). To best collaborate with young people in implementing programs intended to benefit them, public health efforts should thus focus on a youth engagement approach.

Youth Engagement in HIV programs

Adolescence marks the critical time when young people transition from childhood to adulthood. During this time they are more likely to face peer pressure and engage in risky behaviours, which makes it difficult to monitor their health outcomes (CYCC Network, 2013). Within the context of HIV intervention programs, young people

continue to face several barriers in accessing health services (Bekker et al, 2015). Consequently, youth age 15-24 years have continuously exhibited the lowest uptake of sexual and reproductive health services including HIV testing and counselling services (Bekker et al, 2015). Existing literature suggests that young people tend to be reluctant to seek HIV services. These reasons include: stigma and judgmental views from adults, health clinics and services being geographically out of reach, health care settings not being welcoming, health care providers talking down to the youth and not always treating young people as individuals with input that can be valuable (Bekker et al, 2015; Mmari et al, 2003).

Yet, if adult health providers were to meaningfully engage with young people when providing health care services, HIV programs could be more meaningful and effective. This is congruent with a successful youth engagement strategies where youth-adult partnerships can lead to adult health care providers talking to youth about prevention of sexually transmitted diseases including HIV and all other topics related to sexuality, topics that are usually taboo between parents and their teenagers (Coetzee et al., 2014). That is why establishing an equal partnership between young people and adults in the execution of health programs targeting adolescents is a great opportunity for young people to learn about sex from adults outside of their immediate family who are also trained health workers. Likewise, adults working with youth can communicate sexual knowledge and information on risky behaviors to young people in a friendly non-patronizing manner. Successful engagement strategies would therefore feature adults working in youth programs who value the opinions of young people and youth who see adults as supportive allies. In doing so, youth-adult partnerships bridge generational gaps between young people and adult allies.

With the goal of engaging young people to seek health services, the youth engagement approach has been implemented and evaluated internationally in a few public health programs, mostly in Canada and Australia. The Halton health department in Ontario, Canada, recently evaluated a newly adopted youth engagement approach that aims to mitigate the gap between adults working with youth in the community (Halton Region Youth Engagement Report, 2011). The Halton Region Youth Engagement report (2011) contains information on revised best practices when delivering health services to youth in the greater Toronto area. In 2013, the BC Ministry of Children and Family Development created the British Columbia Youth Engagement Toolkit, based in Vancouver, British Columbia. This toolkit gleans information from the valuable work of local community members and health practitioners in collaboration with the Aboriginal and LGBT youth, to create a practical guide for organizations working with adolescents (BC Ministry of Children and Family Development, 2013). The *Australia Research Alliance for Children and Youth* (ARACY), networks academics, youth organizations, health practitioners, and showcase the latest strategies and technology tools aimed to improve the wellbeing of young people in Australia (www.aracy.org.au). All of these youth engagement initiatives employ a participatory research method that seeks to integrate young people as equal partners to adults in making decisions aimed to benefit the youth and positively impact their lives. These youth-adult partnerships enable young people to reach optimal growth as future leaders

by gaining support and guidance from more experienced adults through skills development.

Youth Engagement in the South African Context

According to the latest USAID report, Southern Africa holds the highest HIV prevalence in the world, with an estimated total of 12.7 million people living with HIV (USAID Global Health regional report, 2015). In South Africa, 7.1% of youth and adolescents aged 15-24 years are living with HIV (Coetzee et al., 2014; Shisana, O. et al., 2014). Such prevalence may be due to young people living in South Africa being exposed to multiple socio-structural issues such as a high rate of unemployment, communal crime and a lack of opportunities, thus putting them at risk of acquiring HIV (Naidoo, P. et al., 2015). These social barriers are more prevalent in the urban township of Soweto, where the high rate of poverty is rooted in South Africa's apartheid history (Kautzky, K. and Tollman, S., 2008). The relocation of black South Africans into impoverished township settlements has resulted in the inequitable distribution of opportunities and health services across South Africa (Kautzky, K. and Tollman, S., 2008). Consequently, young people residing in Soweto are faced with several socio-political shortcomings that limit their ability to engage in national youth policies and programs initiated by the government.

To better engage young people in health services intended to benefit them, in 1999 the South African government initiated the National Adolescent-Friendly Clinic Initiative (NAFCI) in order to improve the public health sector's ability to meet the needs of young people (WHO: NAFCI report, 2009). The NAFCI policy has been recognized as a priority within the South African Department of Health, as a way for health care providers working with young people to employ a youth-friendly service approach (Otwombe et al., 2015). This led to the initiation of federal youth engagement HIV programs like *Soul City* and *Love Life*, both of which provide HIV services specifically targeted to youth (Coetzee et al., 2014; Naidoo, P. et al., 2015). These initiatives have successfully implemented a 'youth-friendly' environment in health care facilities, which includes friendlier clinic décor, adult staff interested in working with youth, and flexibility of clinics hours of operation to best serve young people because of their after school schedule (Black et al., 2014; WHO: NAFCI report, 2009). Yet, the NAFCI youth health efforts have not evaluated the impact of the youth-adult partnerships in health programs. It is important to recognize that the NAFCI efforts have been successful in some ways, like the implementation of HIV prevention programs in youth-friendly clinics. However, there is limited literature evaluating the effectiveness of the youth engagement approach of HIV services for young people in South Africa.

The aim of our study is to evaluate the youth engagement (YE) approach as part of a larger HIV research study in Soweto, South Africa. The AYAZAZI ('Knowing Themselves' in Zulu) longitudinal cohort study aims to investigate HIV socio-behavioural patterns and clinical characteristics among young people by providing sexual health and counselling services to this key population. The AYAZAZI study features the establishment of youth-friendly health services coordinated by the Perinatal HIV Research Unit (PHRU) in Soweto, South Africa. AYAZAZI recruitment occurs at the

Chris Hani Baragwaneth hospital, which is the third largest state-of-the-art public hospital in the world. The AYA ZAZI study aims to adopt a youth engagement approach, which includes creating a youth-friendly environment for adults and youth staff members and, more importantly, for the Adolescents and Young Adults (AYA) AYA ZAZI research participants. The AYA ZAZI youth-friendly clinic is a safe space that is non-judgmental and does not resemble the setting of a typical clinic; rather, it is a space that is reflective of the modern-day youth culture and preferences. This includes the creation of a youth lounge with a computer, printer, and digital tools for teaching youth about education and searching for jobs.

The AYA ZAZI cohort study recognizes the importance of implementing the youth engagement approach within its study design. Target goals were outlined in the AYA ZAZI youth engagement manual established by the research staff. This document identifies key indicators that will be used to assess the impact of the youth engagement approach. These indicators include: appropriate structure, supportive relationships, and opportunities for skill building. Appropriate structure is a non-judgmental and inclusive environment for young people. Supportive relationships include consistent adults supporting young people and promoting empowering practices. Opportunities for skill building are defined as an environment that gives young people the platform to build skills and competencies that goes beyond the study. This youth engagement approach as part of the AYA ZAZI study is a participatory research approach that collaborates with adolescents as co-researchers in providing critical input that can improve study efforts.

The aim of our evaluation is to assess the Youth Engagement (YE) framework as part of the AYA ZAZI cohort study. The findings from this evaluation can help contribute to the current South African Youth policy, and to address gaps in the literature to provide evidence-based standards to best engage young people in health services intended to benefit them. The overarching goal of this evaluation is to inform policies and programs targeting young people as a way to support their inclusion as decision makers and equal partners for programs intended to benefit them, while receiving the support of adults as allies.

METHODS

The AYA ZAZI cohort study

AYA ZAZI is a three-year prospective longitudinal cohort study that aims to link socio-demographic, behavioural, and clinical characteristics of youth age 16-24 years. Recruitment takes place at two sites in South Africa: Soweto (Gauteng state) and Durban (KwaZulu-Natal state). Recruitment in Soweto and Durban began in 2014 and 2015 respectively. The Canadian Institutes of Health Research (CIHR) has funded this research project with principal investigators from Simon Fraser University (SFU) in collaboration with researchers at the Perinatal Research Institute of HIV Research Unit (PHRU), a university of the Witwatersrand (WITS) syndicate.

The present youth engagement evaluation was performed at the Soweto site where AYA ZAZI operates at the Perinatal HIV Research Unit (PHRU), a research

syndicate of WITS University. The PHRU serves the local Soweto Township as one of the HIV research and clinical centers run through Chris Hani Baragwaneth Hospital. The AYA ZAZI cohort study is conducted at the Bio-Behavioural Research Unit (BBRU) of the PHRU. The BBRU is an adolescent health center that provides HIV testing, counselling, sexual and reproductive health services for young people age 14-24 years. At the BBRU, half of the staff members are youth (16-24 years) living in Soweto and within the same age group as the key studied population. The other half of the staff are adults over 25 years who are trained counsellors, project managers and clinicians. The Adolescent and Young Adult (AYA) AYA ZAZI research participants, were recruited at the BBRU in 2014 when the study first started.

As part of the AYA ZAZI study, demographic data (including age, place of residence, education) and clinical data are recorded for all Adolescents and Young Adult (AYA) participants at enrolment and every six months for the next three years. At enrolment, participants are asked to complete a detailed interviewer-administered questionnaire that collects data on sociodemographic and characteristics, sexual and reproductive history, substance use, mental health, and technology use. Blood samples are drawn for HIV testing and other sexually transmitted diseases including gonorrhea, chlamydia, syphilis, and herpes simplex-2 (genital herpes). At all study visits, participants are provided confidential counselling services, and data are collected from medical interviews and physical examinations by a clinician.

Eligibility criteria for AYA ZAZI are being between 16-24 years of age, residing in the Soweto region, and willingness to provide written informed consent (or parental/legal guardian consent for minors under 18). At the time of our youth engagement evaluation, a total of 200 participants had been enrolled in the AYA ZAZI study in Soweto and had returned for their six month study visit. AYA research participants were recruited through youth staff members receiving referrals by community outreach programs and by word of mouth.

The AYA ZAZI cohort also features an Adolescent Community Advisory Board (ACAB). The ACAB is a voluntary committee initiated by the BBRU, and they run monthly meetings at the PHRU to ensure that study protocols and surveys are representative of the Soweto youth community. This is a youth engagement approach, where the ACAB is heavily involved in the ongoing revision of the design, conception and implementation of youth outreach in all projects at the BBRU, which includes the AYA ZAZI cohort study.

As part of a youth engagement approach, all study personnel worked actively with AYA study participants to secure physical and mental support, for example by providing counselling services, creating a youth-friendly environment at the clinic, and always providing refreshments to AYA research participants. At each study visit, AYA research participants received an honorarium of 50 South African Rand (ZAR; approximately CAD \$4.50) and a driver was hired to pick up participants to and from the study site.

The aim of our study was to evaluate the youth engagement approach based on the predefined indicators (appropriate structure, supportive relationships, opportunities for skill building), as part of the AYA ZAZI cohort study. The evaluation of the youth engagement approach was conducted at the PHRU in Soweto between May and July 2015.

YE Study Design

The YE evaluation was conducted from April-July 2015. It employed a qualitative participatory research action (PAR) approach. The PAR approach aims to engage youth as active co-researchers who provide valuable input for research designs to be more youth-friendly in data analysis and developing creative dissemination strategies, with the ultimate goal of putting their ideas into action (Flicker et al., 2008). For our sub-study, we aimed to evaluate the experience of both the AYA ZAZI study participants as well as the experience of the youth and adult study staff. We did so by drawing upon two data sources (1) anonymous feedback received from AYA ZAZI participants on areas for improvements (collected via a suggestion box), and (2) Semi-structured interviews with select AYA ZAZI participants as well as youth and adult staff members.

Suggestion box

At the AYA ZAZI baseline study visit, AYA research participants were given a set of questions and asked to write answers to be inserted anonymously into the suggestion box. New sets of questions were drafted in April 2015 to be implemented at the first (6-month) study visit; these new questions specifically aimed to assess if AYA participants engagement with the study had changed since baseline. The present study focused only on the answers provided to the new (April 2015) set of questions.

From April to July 2015, a suggestion box was placed in the youth clinic of the BBRU for AYA research participants to voluntarily answer a set of questions at their six months follow-up study visit. All questions and answers were written in English; all responses were anonymous. This was a way to create an ongoing dialogue with AYA ZAZI (AYA) participants, by gaining their insights as collaborators who make informative decisions on what the AYA ZAZI study needs to change in order to continuously improve its youth-friendly clinical practice.

The suggestion box questions were as follows:

1. Do you have suggestions for improving AYA ZAZI?
2. How would you rate your experience today compared to your last study visit?
3. What types of events would like to see take place?

Participant and staff interviews

The second source of data was from semi-structured qualitative interviews of AYA ZAZI staff members. Questions were created to best evaluate the engagement of the AYA study participants with the AYA staff members. Face-to-face interviews were conducted in English.

AYA research staffs were asked to recruit five Adolescent and Young Adult (AYA) research participants between the ages of 18-24 at their six months follow up visit to undergo a semi-structured interview. Participants had to be over 18 years old, male or female, and willing to be audio-recorded for a short interview. In addition, a brief email was sent to all AYA ZAZI staff members, youth and adults, asking them to voluntarily participate in a face-to-face interview. To get an equal representative sample of youth and adult staff, four youth (AYA) staff members (age 16-24), and four AYA ZAZI “adult ally” staff members (25 years or older) were selected for interviews. All interviews were conducted in July 2015 at the AYA ZAZI study site.

Interviews featured open-ended questions, using a conversational and informal approach to allow AYA ZAZI participants as well as staff (both AYA and youth) to talk about their experiences as members of AYA ZAZI. To avoid research biases, the research interviewer remained neutral and emphasized to all participants that there are no right or wrong answers. The interviewer also emphasized that the interview was voluntary and could be terminated at any time. Three AYA ZAZI youth engagement indicators were assessed for our evaluation: appropriate structure, supportive relationships, and opportunities for skill building. These indicators informed our interview questions, which includes:

AYA ZAZI Adult Staff Questions

1. In your experience as an AYA ZAZI staff member, do you think the Youth Engagement (YE) approach has helped create more of an equal partnership between AYA ZAZI adult allies and AYA staff?
2. What about between adult allies and AYA participants?
3. Can you explain more about your answer?
4. What are some of the challenges that you can identify (both for yourself personally and for your work at AYA ZAZI) when you think about the AYA ZAZI YE approach?
5. What are some of the strengths that the YE approach has brought to the AYA ZAZI study?
6. Do you feel you have learned/developed any new skills while working on the AYA ZAZI study?
7. If so, can you explain?
8. What are some ideas that you think could help create a better environment for both adults and AYA to be more engaged in AYA ZAZI?

AYA ZAZI (AYA) Youth Staff Questions

1. In your experience as an AYA ZAZI AYA staff member, do you think the Youth Engagement (YE) approach has helped create more of an equal partnership between AYA ZAZI adult allies and AYA staff? Can you explain your answer?
2. What are some of the challenges that you can identify (both for yourself personally and for your work at AYA ZAZI) when you think about the AYA ZAZI YE approach?
3. What are some of the strengths that the YE approach has brought to the AYA ZAZI study?

4. Do you feel you have learned/developed any new skills while working on the AYA ZAZI study? If so, can you explain?
5. What are some ideas that you think could help create a better environment for both adults and AYA to be more engaged in AYA ZAZI?

AYA ZAZI Participant Questions

1. Do you feel that your time was well spent during your AYA ZAZI study visit today? (This includes interviewers, nurses, counsellors, driver, etc). Can you explain more about why you said “yes” or “no”?
2. What ways would you suggest that we could better meet the needs of young participants like yourself?
3. What part of your experience with AYA ZAZI do you enjoy the most? Can you explain more?
4. What part of your experience with AYA ZAZI do you enjoy the least? Can you explain more?

Data Collection and Analysis

For the AYA research participants, answers submitted to the suggestion box and interview questions were designed to assess the impact of the AYA ZAZI YE approach, by seeking the input of AYA research participants in creating a more youth-friendly environment at the clinic and ensuring that their participation in the AYA ZAZI longitudinal study was worthwhile. For the AYA ZAZI staff members, interview questions were asked to evaluate the professionally based youth-adult partnership, and seek ways to improve the YE approach. All interviews were audio-recorded and transcribed. By April 2015, almost half of the AYA ZAZI research participants had completed their six months follow-up visit and could not answer questions for the revised suggestion box. The remaining AYA research participants (n=110, 55%) were asked to anonymously answer a set of questions for the suggestion box at their six months visit, five recruited AYA research participants participated in the face-to-face interviews, and eight AYA ZAZI adult and youth staff completed the face-to-face interviews.

Suggestion box questions and interviews were conducted in English and transcribed into Microsoft word. All interviews were voluntary, with no reimbursement or compensation. Face-to-face interviews were done in a private room, lasted about 15 minutes on average, and were audio-recorded. For the face-to-face interviews, semi-structured open-ended questions were designed to gain the insight of both AYA ZAZI staff members and AYA research participants, on ways to gain their perspectives on the youth engagement approach and potentially identify ways to inform future youth-friendly services. Transcribed data from the interviews were analyzed on the basis of the questions that were asked. Findings from these interviews are intended for the AYA ZAZI adult allies (i.e. AYA ZAZI adult staff members) and Adolescent and Youth Adult (AYA) staff members to continuously receive ongoing training and capacity building based on the AYA ZAZI Youth Engagement approach.

Ethics

The AYA ZAZI youth Engagement valuation study was approved by the Institutional Review Boards of the University of Witwatersrand (WITS), Johannesburg, Human Research Ethics Committee (HREC), and the Simon Fraser University Research Ethics Board. Questions were piloted with the support of the AYA ZAZI team at the PHRU, with the approval of the University of WITS HREC. AYA ZAZI staff members and study participants conducted the interview after giving written informed consent for the One-on-One semi structured interviews and audio taping. No compensation was allocated for their participation.

RESULTS

Suggestion Box

After reviewing all suggestion box answers collected between April 2015 to end of July 2015, out of 110 AYA research participants that were asked to respond to the suggestion box, most of them were essentially blank (30%), others felt that nothing about the AYA ZAZI study needed changing or they had minimal informative answers (20%), some were incomplete with approximately one of three questions answered (20%). Such answers were deemed not substantial for our study findings, therefore excluded. Transcription and data analyses of answers only included responses from AYA research participants that highlighted successes of the study or answers that would provide feedback on areas of improvement needed for the AYA ZAZI youth engagement approach. Reasons for AYA research participants not giving more in-depth responses to the suggestion box questions, could be that for many of them English is a second language, others might have wanted to quickly leave the clinic after spending long hours conducting the AYA ZAZI study (counselling, clinical testing, administrated survey). All suggestion box feedback were continuously shared with the AYA ZAZI team throughout the youth engagement approach evaluation study process, instead of waiting until the end of the study to implement suggestions made by AYA research participants.

From the suggestion box answers, approximately 30% (n=35) of the total answers were transcribed to examine, compare and search for similarities and differences throughout responses that provided substantial content for the AYA ZAZI youth engagement approach. Random selections of responses from the suggestion box were categorized by major themes underneath the most reoccurring answers, by recognizing similarities between answers and further summarizing it into consolidated sub-categories by the most common elements. Suggestion box feedbacks from AYA research participants included the following elements: (1) communication with counsellors, (2) technology-based tools, (3) access to food, (4) increased education, (5) Clinic wait time, (6) Community engagement.

Communication with Counsellors

Respondents' positive experiences with the counsellors. AYA research participants (n=8) mentioned that they were able to engage in longer conversations with the counsellors at the second visit, as one participant put it, 'at this visit I could get counselling that made me feel better inside and out'. Others (n=15) mentioned that they

enjoyed chatting with counsellors as a highlight of their clinic visit. This shows an improved dialogue between the youth and the older staff members during the counselling sessions, in comparison to the initial study visit at baseline.

Technology-based Tools

Respondents description of incorporating more technology-based tools into the study were mixed. Most respondents suggested having Wi-fi access (n=13), and providing more video game options (n=4) would make the clinic more youth-friendly. Others expressed their desire for the study to use computer-based assessments instead of paperwork (n=7). Three participants stated: “more use of computer technology than paper work”, another suggested ‘you must start using laptops because this paperwork of yours is eating up a lot of time’. To the best of our knowledge, according to the AYA ZAZI research protocol, the only paperwork needed from AYA research participants is for the baseline informed consent forms. Whereby AYA research participants are asked to provide permission for their willingness to participate in the study, and they are no longer asked to sign forms at other follow-up visits. For participants who are minors at the study enrollment, they have to sign the informed consent forms again at the age of 18. It is unclear in what capacity the use of technology could address the exhaustive time spent on paperwork.

Access to Food

When asked about what they liked the most about the AYA ZAZI study, participants (n=10) highlighted that they liked the provision of ‘hot dogs and bread for lunch’. This is different from other participants (n=2) that suggested that the AYA ZAZI study offer AYA research participants healthier snacks after each study visit, as indicated by a respondent ‘by providing food that can give back energy. I mean we need food after so much blood had been taken. Coffee, juice and cakes don’t really give vitamins’. The second suggestion was taken into consideration by the AYA ZAZI staff and raised at the following week team meetings. An immediate plan of action was implemented to provide more fruits and vegetables to AYA research participants.

Increased Education

Participants’ reports on their satisfaction of HIV knowledge was mixed. Some answers from the suggestion box (n=9) reported that AYA participants were content with their HIV-related learning, while others (n=4) indicated that the AYA ZAZI study needs to enhance opportunities to learn about HIV. This is different from other AYA participants who said that they learned more about HIV prevention at their follow-up visits in comparison to baseline (n=6): ‘Today I learn three ways of getting HIV’. Because these were anonymous and voluntarily answered questions, it was not possible to probe participants to further elaborate on what exactly they newly learned from the study or what they would like to further learn, especially in relation to HIV prevention.

Clinic wait time

Answers provided by participants on clinic visit wait time were mixed. On one hand, participants (n=8) indicated that the AYA ZAZI study could improve its management of time when delivering services to participants at each study visit, while

other participants (n=4) stated that, the follow-up visit was shorter and quicker than it was at baseline. Mixed answers on study clinic visits wait time may be due to the efficiency of staff responsiveness to participant feedback: suggestion box inputs were discussed at each weekly AYZAZI team meetings and immediately addressed if possible. The AYZAZI staff was able to identify gaps in visit wait time, and collaboratively came up with a strategy to make AYA research participants visits more efficient and enjoyable. Indeed, feedback regarding improved clinic wait times was received following the implementation of this strategy.

Community engagement

To best engage AYA research participants and make their participation in the study worthwhile, it was important to seek their input on engagement events and activities. Common suggestions from participants included, more events centered on learning while having fun (n=7), more singing and games to engage with other peers (n=5), and community-based outreach events to raise awareness of the study (n=2). Some of these suggestions go beyond the protocol parameters of the AYZAZI study, like community outreach events, therefore the AYZAZI team was unable to implement it.

Face-to-face Interviews

For the qualitative interview, the aim was to assess the AYZAZI youth engagement benchmarks (appropriate structure, supportive relationships and opportunities), during the face-to-face interviews with AYA research participants and research staff.

Appropriate Structure

As part of the youth engagement approach, a safe space is critical to the success of establishing a youth-adult partnership. The physical space should be representative of youth culture and preferences, like having a television and computer connected to the internet at the clinic in the waiting room. This is for AYA participants to be part of a delightful environment that keeps their mind away from personal life troubles, or alleviates the stress of conducting HIV clinical testing. As a result, the AYZAZI clinic created a youth-friendly space with a computer and printer, which were used by AYA participants for resume building, university and job applications.

“The youth engagement approach, what it has done to the AYZAZI study, is that it has created an environment into the clinic that is youth-friendly, so it’s not your typical clinic. It is a space that smells like a theatre, not like injections or needles or medicine. So the youth feel more at ease when they come in, the environment is a bit more chill as opposed to your average clinic.” – AYA staff member (1)

“Also the setting is not your typical clinic environment, like the typical smell in clinics where there are injections involved. The AYZAZI lounge, it is accommodating where they [participants] have access to the Internet, play games, and also get any general information and constantly checking up on them to see if they are okay or need anything. [Ummm] Reassuring

them when visitors may be taking longer, finding out how they are doing, do they have any concerns or complaints? What would they like to improve with our services.” – Adult staff member (1)

This safe space has led to the creation of an informal setting where vulnerable youth that are participants of the study, often visit the youth and adult staff beyond clinic hours to build rapport on their day-to-day challenges. This has helped create a strong relationship between the adult staff and young participants by breaking certain communication barriers:

“They even sometimes come for an unannounced visit ‘I just came to see you’. I think its about creating that safe space, where they feel comfortable and not judged, understood, heard, and they know that there is someone who can talk to them regardless of what they talk about. I think that in some of the projects that we do, the limitation is that, whatever has been discussed can only be limited to the procedure of the study. Whereas with us, it’s so open that we talk about all aspects of their lives. Be it relationships, [Ummmm] school, be it their community, friends, so it’s not limited to only to see behavioural change [as part of the study protocol] it doesn’t mean we don’t look at the person holistically from that angle.” - Adult staff member (2)

This safe space is a success because of the engagement of the young staff members with participants of the same age group, whilst the adult staff members have learned to improve their communication skills with young staff members and participants to best speak to one another on an equal playing field:

“On my side, as young as I am, working with young people it became easier ‘cause we are able to understand each other, the languages, the prime standard of talking to them, it was easier to approach them.” – AYA staff member (2)

“I would say that it has, the reason being that, I have observed that all of our staff we try our best to be at the level of the youth. By not always coming across as professional, I think first and foremost. Although there is that element of professionalism, but when you are addressing the youth, from my personal experience, we try as much as possible to use their language and terms that they are using. Also giving them equal opportunity to voice their concerns and views, giving them a platform to talk, be open and free. But most importantly, it is about the atmosphere. You know, when you are around them, you don’t have to be exactly like them but you try to accommodate them as the youth, by the way they talk, the type of language and terms they use. But also clarifying, because some we are not always familiar with the terms that they use. Clarifying in a safe approach and environment, where they do not feel judged or discriminated.” – Adult staff member (3)

But as suggested by a few AYA staff members, a collective involvement at a deeper level from both the young and adult staff in the lives of the young participants is needed beyond the décor of the clinic. Specifically, the study needs to go beyond simply providing refreshments and entertainment for the study participants during their visits, and aim to really meet critical needs outside the clinic such as food insecurity or a lack of clothing:

“The environment that we can create may be coming with the idea that when the participant comes in and finds out that the participant, he or she has hard access to food. May be buying some packages of food for that participant to take home. For the people like, those who don’t have clothes, maybe the staff can come with clothes and hand it over to the participants as a donation.” – AYA staff member (2)

“The most important thing is having to be attentive to what they are saying, also in comparison to their body language. Being able to identify that [body language] first, and inform them that you have seen where there is a discrepancy, for example you are saying that you are happy, but yet you look sad or you look a bit tense or you are feeding with your hands. So, basically opening up so that they are aware that it’s not only about me capturing something that is needed for the study, but I can actually see that there’s actually something bothering you.” Adult staff member (2)

Although refreshments are continuously provided to the young participants at each study visit, food insecurity and a lack of clothing are pressing issues faced by young participants. This may need to be addressed at staff meetings, as the youth may not feel comfortable mentioning these in the suggestion box.

Supportive relationships

Through regular weekly meetings and the initial youth engagement training session offered at the start of the study, both adults and young staff have learned to effectively work as a team and communicate with one another what their immediate needs might be. This has also enabled the young staff to seek advice and acquire new career competencies from the older staff members, while the adults have learned a lot from the work dynamic of the younger staff, which differs from working with adults in the corporate world:

“Through the youth engagement, I have gained so much from the support of senior staff members, who have showed how to implement certain things within the project. You have this constant feedback between the young and older staff members, which makes it great because whatever you want to implement, you receive it from different angles.” – AYA staff member (2)

“I am used to dealing with adults. There is always that element of talking seriously with adults with limited fun. With adults it’s often strictly business. With the youth, there is an element of fun, we have to always

redirect them you know? In a fun, friendly, respectful manner to them so that they may understand what you are saying.” – Adult staff member (1)

Despite the youth-friendly environment and mutual respect between the adults and AYAs, age gaps remain a barrier to both groups being able to relate to and support one another on an ongoing basis. Adults often struggle with addressing issues with the adolescents, who at times are more sensitive and may not be used to direct feedback from an older person, while the younger ones often feel uncomfortable addressing issues to the adults as a means to not undermine their authority:

“You might find that, in the team as we are working as young as we are, sometimes you want to be that serious. I am not saying seriousness about your work, I am saying that the laughter, the little bit of playness *Nyana* (Sesotho: sort of; a little bit of), yeah for older people it’s hard to do that. Sometimes you might think that this person is very old so I can’t bring some ideas to them, things like that.” - AYA staff member (4)

“The youth engagement approach, like I said before, challenges are [Ummm] working as a team within different age groups, and I think that also [Ummm] I don’t know how to put it, but it may be difficult for older staff members to gain instructions from younger staff members, because there are still this hierarchy that older people instruct the younger people. But here, because we are such a mixed group of different levels of education and background that we have, sometimes it is not preventable that younger staff members also need to instruct the older ones.” - Adult staff member (3)

To best address this issue, an adult staff member mentioned the importance of including a debriefing session as part of the weekly team meetings. To implement this idea, a bi-weekly debriefing counselling session takes place as a team, where daily challenges in working with vulnerable youth are addressed among all staff members, and strategies are given to all staff members to best deal with team power dynamics and hierarchy. This is a space where staff members can feel comfortable vocalizing their concerns when working together.

Opportunities for skill building

For the adolescents and young adult (AYA) staff, it was mentioned that working with young people of the same age group has allowed them to improve their ability to communicate effectively with young people of the same age group without being judgmental, and learning to be more open-minded about learning new things about the lives of other youth living in the same community. Communication was a reoccurring theme mentioned across all groups:

“Because the older staff that we have, they are able to adapt to the younger ones. [Ummm] I believe that the youth engagement has been helped, because [Ummm], all in all, the communication between the elders and younger ones are able to be informed and they are able to get more information about what they do not know. [Ummm] The young ones

are able to get more information from the older ones.” - AYA staff member (2)

“All of the staff members we got training, I think It was about 14 hours training on how to engage with young people. And the fact that in the study, we also have young people like myself, it also helps the adults to understand how to deal with young adults and adolescents that come in. I think that it’s helpful. So the training actually taught us that, with young adults you have to understand that they are actually sensitive, and for them it is important to always remind them that everything they say to you is confidential and it will stay with you, you are not going to tell anyone unless they [young people] agree to give you the permission to go and do so. It helps because on a day-to-day basis, they also feel comfortable with us now, they are able to say we like the way you treat us, we like 1, 2, 3 that you have implemented, so and so is cool.” – AYA staff member (4)

Skills like communication, confidentiality, humility, continuously listening and engaging young people, while speaking to them in a manner that is reflective of what they will understand, appear to be crucial components of how adults are able to best speak to the youth:

“The youth they are not quite familiar with the concept of counselling. So it becomes difficult for them to easily and openly talk about their experiences, you know? It has to reach a point where they feel like they can talk about their experiences. But it also goes back to how we as staff interact with the youth, like I said, talking in their language and understanding them from their frame of reference. And not trying to impose our intellectual knowledge onto them. If you are using difficult phrases, like for example on consent forms we use words like ‘genetic testing’, ‘reimbursements’, if those things are not clarified for them it tends to be confusing and they tend to not understand what it is the purpose for them being in the study, you know.” – Adult staff member (4)

“I had time to get checked up again because it’s not been six months because I needed to be sure that everything is still the same. I like my time with the counsellors the most, because we get to talking, and sometimes she [counsellor] shares something that is life opening for me.” – AYA participant (2)

“I like counselling a lot, because I always meet kind people [counsellors]. They explain everything to you and you understand everything they are saying. They explain everything about sex and the results. ” – AYA participant (3)

DISCUSSION

The youth engagement framework is a relatively new participatory research approach that involves the meaningful participation and sustained involvement of young people in activities intended to benefit them (Pereira, 2007). With a limited but growing body of literature supporting the impact of youth engagement in health research, our study sought to evaluate this youth engagement approach as part of the AYA ZAZI HIV interdisciplinary cohort study in Soweto at the six months follow-up visit. The AYA ZAZI HIV longitudinal cohort study engaged youth by recruiting young people (16-24 years) as both research participants and staff members.

This project shows how the AYA ZAZI study took concrete actions towards adopting a youth engagement approach. Youth engagement was achieved through a number of actions, including the continuous implementation of feedback received from Adolescents and Young Adults (AYA) participants through the use of a suggestion box. Other actions taken by the AYA ZAZI study include staffing young adolescents on the AYA ZAZI team and hiring a team of adults who are not only cognizant of youth health, but also active in advocating for adolescent capacity building.

The suggestion box was a tool that gave AYA participants the opportunity to communicate areas of success of the AYA ZAZI study. For example, one success highlighted by youth was the generous time spent with counselors at the follow-up visit in comparison to baseline. The suggestion box also highlighted areas of improvements; for example, suggestions were made to improve the physical space of the youth lounge to make it more youth-friendly.¹

The second part of our study conducted face-to-face interviews that assessed the AYA ZAZI youth engagement indicators: appropriate structure, supportive relationships, and skill building. Our study identified the need for ongoing professional development training on the topic of youth engagement in order to address the inherent power dynamics in the work environment between youth and adult staff. Findings from our study support the idea that the implementation of the youth engagement approach is feasible when there is a structure in place that supports ongoing dialogue between young people and adult allies.

The suggestion box allowed participants to directly engage with the study's staff by vocalizing what part of the study and services at the clinic can be improved to meet their needs. Responses from the suggestion box included the creation of a youth-friendly space, which was later implemented with ongoing feedback from participants. Making the clinic more youth-friendly has allowed participants to have a safe space when they visit even outside their scheduled study visits. They voiced that they felt comfortable bringing in their friends. This creates an opportunity for AYA participants and their peers to get informed on HIV prevention services and methods and take part in future HIV-related studies.

1. One such example was improving internet connectivity within the clinic.

Another great success of the youth engagement approach in AYZAZI was the collaboration and supportive relationships between adult and youth staff. Although there were barriers to effective staff teamwork in the form of power dynamics due to age differences, ongoing communication created an effective partnership between the two groups. Both groups were able to humbly understand one another and, in the end, learn from each other. Through this sense of belonging to a collective with a greater purpose, of improving the healthcare services of youth living in Soweto, the partnership between adults and youth partnership created an enthusiastic and energetic environment where effective decision-making ideas were exchanged between the diverse groups.

The study findings also indicate that there is a need for continuous training and refreshers of up-to-date youth engagement practices. This speaks to one of AYZAZI target indicators: appropriate structure. While the initial training for the youth engagement approach at the start of the study was a great introduction to the Youth Engagement Framework, ongoing training is needed to continuously improve each team member's practice and roles. This could help all staff members, youth and adults, to find further solutions to their individual challenges when working with participants or colleagues of different age groups. This training could also provide a space where the hierarchy between adults, who hold a higher level of education and have more job experience, and the youth staff, can be mitigated. The training provides an opportunity for ongoing dialogue on the challenges these two groups face in sharing power especially when youth want to provide professional advice to their older colleagues.

LIMITATIONS

The study's overall results should be interpreted and implemented in other adolescent research projects in light of some limitations. Unlike the AYZAZI interview-administered survey that is verbally translated for participants in their South African language of choice, the youth engagement evaluation face-to-face interviews were in English with no language assistance from AYZAZI South African team members. As such, there was a language barrier when the interviews were conducted with the AYA study participants, as none of them spoke English fluently. Unsurprisingly, it was a challenge for AYA participants to provide informative answers on their perspectives of the study's youth engagement.

The language barrier was also a key reason for the limited success of the suggestion box. The majority of suggestion box responses were left blank or incomplete, as some participants might have simply wanted to exit the clinic after spending long hours participating in the AYZAZI study. While AYZAZI staffs were asked to encourage AYA research participants to answer suggestion box questions before leaving the clinic, there was no mechanism in place to ensure that participants filled out the suggestion box questionnaire. There was also no way to ensure that staff continuously communicated this youth engagement tool to participants.

Another weakness of the suggestion box was that some answers written by participants seemed vague and had limited elaboration. Because participants were asked to fill out suggestion box questions on a voluntary basis, it was not possible to

probe for deeper answers. For future youth engagement approach evaluation tools, it could be useful to find other mechanisms to create an ongoing dialogue with adolescents to provide more qualitative insights.

Moreover, the interviews were an evaluation of the professionalism of the youth engagement approach in the AYAZAZI study. 'Courtesy bias' might have led some participants and staff members to not provide any negative feedback on the study. Lastly, this was a qualitative study that took place at the PHRU in the BBRU and only five adolescents were interviewed in total. As such, the results presented may not be generalized to the entire South African youth population.

IMPLICATIONS

Very few published studies have evaluated the Youth Engagement approach from the perspective of adults and young people simultaneously. Despite the limitations mentioned earlier, the AYAZAZI study has demonstrated that it is possible for adults and young people to productively work together. Regular ongoing training that is up-to-date and refreshers of ongoing difficulties encountered by staff members could bridge communication gaps between staff members of different age groups. This approach should be implemented in policies, initiatives, and programs aimed towards youth. Where young people are involved as equal partners with adults, the participation of these young people in the decision-making of programs targeting their age group is crucial in ensuring these programs' effective engagement. While for adults, the involvement of young people as equal partners allows for an exchange of knowledge from a newer perspective. Adults may be able learn new strategies, contemporary culture, and ways to conduct their work differently. Youth benefit by learning professionalism, career perspectives, and life experience from older staff. Rather than minimizing the involvement of young people in programs aimed to benefit them, more policies that foster youth engagement should be developed. For example, young people should be hired on staff and actively engaged. Strategies should be implemented that strengthens an open-communication policy where the input of youth are taken into consideration and are meaningfully put into action. This way, young people feel appreciated and valued by the adults, while adults become more willing to gain insights from the young ones.

REFLECTION

In the Masters of Public Health program, specifically in the Global Health Stream, we have extensively studied the complexity of vertical approaches rooted in colonial history. That is why global health practices now intend to employ diagonal interventions, where western funders equitably collaborate with those in the global south, while adopting a holistic health systems approach that prioritizes community members.

As seen with the AYAZAZI youth engagement approach, when given the right support and opportunities, young people can thrive and become unstoppable. It was truly humbling for me to see adolescents from low-income settings be hired on a research project and play such a key roles in the success of an HIV prevention program. Employing a qualitative participatory action research approach was also new

to me and made me appreciate qualitative design methods. With ongoing feedback from the suggestion box, informed interview questions, the AYZAZI team did their best to allocate resources to meet the needs of the youth. This research approach is truly powerful. By valuing youth input and giving a voice to this marginalized group as meaningful decision makers in research projects intended to inform policies that will impact their lives, the youth engagement approach was a revelatory and ethical way to assure that health interventions are equitable.

This study has successfully achieved an equal partnership between western research and those in the global south. Canadian researchers have an equal gain and shared benefit with those at the PHRU and community members in Soweto are given priority to be hired at the PHRU. Young Soweto staff members are able to engage as collaborators in making sure that their needs can be met through research projects aimed to benefit their cohort and their community.

Seeing the overall organization of the PHRU in meeting the needs of local community members was a great way to visually understand the implications of a diagonal approach to global health, where capital resources are coming from the northern sphere, but cultural knowledge and physical resources are from the community. Also, gender equality seemed to be strongly valued at the PHRU. For me this was truly critical because in low-to-middle income countries, as seen in Sub-Saharan African countries like Congo where I am originally from, women have historically been unfairly treated in comparison to their male counterparts. This continues to affect women's economic autonomy and health. The PHRU seems to have made a conscious effort to provide equal employment for both men and women of different South African ethnic backgrounds.

Also, a large percentage of staff members at the PHRU are people living with HIV. With widely available treatment in South Africa due to successful international global health interventions, many of my colleagues at the PHRU have had many lived experiences within the context of HIV research in South Africa. This is one of the largest contributing factors as to why the PHRU is able to provide such a high level of meaningful research that influences national-level policies. As someone who was originally born and raised in a Sub-Saharan African country that endured years of colonial oppression and years of bad governance, I often feel powerless or hopeless in knowing how to best influence change within the context of a low to middle income country, especially within the context of Sub-Saharan Africa.

My experience at the PHRU in South Africa served as a great example of how public health practices and research propel change not only at a national level, but also internationally. As a student, the academic world and theories read in classrooms in a western setting can often feel detached from the reality occurring in countries in the global south. Being able to apply all of my knowledge that I learned from the MPH program in a supportive setting like the PHRU was truly life changing. It has tremendously and positively impacted my career aspirations in global health by giving me more structure moving forward as a public health practitioner in the global context.

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